

**Report From the Extraordinary Funding Work Group  
to SRS - HCP Community Supports and Services Leadership  
March 2006**

**History**

In the fall of 2003, SRS convened a group of stakeholders (see attached list of members) to review the current status in the State regarding whom is determined eligible and whom receives extraordinary funding for the services provided to individuals receiving services through the Kansas Home and Community Based Services Waiver for persons with Mental Retardation and/or Developmental Disabilities (HCBS-MR/DD). In addition, the group was specifically empowered with the task of making recommendations to SRS-HCP/CSS on the type of assessment tool that will be implemented statewide to evaluate any person applying for extraordinary funding.

Over time, the group has spent many hours looking at a variety of tools currently being used by the 27 Community Developmental Disability Organizations across the state. In addition, SRS contracted with the University of Kansas Center on Developmental Disabilities to examine the efficacy of the recently developed Supports Intensity Scale (Thompson, et al, 2004a) to predict or examine extraordinary support needs for Kansans currently receiving supports from the Department of Social and Rehabilitation Services.

The purpose of this report is to provide feedback to SRS-HCP/CSS regarding the outcome of the research of the Supports Intensity Scale and to offer alternative recommendations with regard to the future of a more consistent method for establishing the need for extraordinary funding for individuals in the Kansas MR/DD service delivery system.

**Feedback on the Supports Intensity Scale**

**Reliability and Validity Concerns**

Members of the Extraordinary Funding (EF) workgroup prefer a valid and reliable instrument, one that has been standardized on a large population. The members agree that the need for extraordinary funding is the result of an individual having extraordinary health and/or behavioral needs. The creators of the SIS also agree, as it is stated on page 4 of the report, "An underlying assumption is that certain medical conditions and challenging behaviors predict that a person will require increased levels of support, regardless of her or his relative intensity of support needs in other life domains". Although Section 1 of the SIS is standardized, the separate Exceptional Medical and Behavior Supports Needs Section (Section 3) is not. The Supports Needs Index (SNI), a score based on the standardized Section 1 of the SIS and which is the independent variable used throughout the study, does not address exceptional medical or behavioral support needs yet would be the indicator of the need for EF if the SIS was adopted to determine extraordinary need for funding. The developers of the SIS have two

suggestions to deal with this issue. One involves determining the SNI then using “clinical judgement to trump any classification level identified through scores from Section 1, The Support Needs Scale” (pgs. 23-24). Using either of these two methods entails using the standardized Section 1 of the SIS even though, as previously stated, “certain medical conditions and challenging behaviors predict that a person will require increased levels of supports, *regardless of her or his relative intensity of support needs in other life domains*” (emphasis added) and then using the non-standardized Section 3 of the SIS along with either non-standardized clinical judgement or non-standardized predetermined criteria to increase the level of support.

Another concern with using the SNI as an indicator is that the respondents are required to guess the degree of support that would be necessary in areas where the individual is not getting support. This would inflate the individual’s score and the state would in essence pay for supports that an individual isn’t getting and probably doesn’t need.

Reliability is an concern. According to the creators of the SIS, inter-rater reliability is “fair” (pg. 29). However, according to the study, inter-rater reliability was “very high across all sections” (pg. 58). The creators of the SIS conducted reliability checks with raters completing the SIS at different interviews with the same respondents; the study conducted inter-rater reliability with both raters attending the same interview. It would be likely that when both raters are observing the same interview, they would hear the same thing and record the same or nearly the same thing. If the interviews were done separately, the interview may proceed differently with different questions asked leading to different responses from the respondents and result in lower inter-rater reliability. What this means for us in Kansas is that if we have more than one interviewer, we can expect that a particular SNI score reflects the difference in interviewers in addition to support needs.

### The Dependent Variable

The report indicates that a good dependent variable was not available. Receiving EF is not a good dependent variable because “as the study progressed, it became evident that this was not going to be a valid indicator of true support needs and of limited utility in determining the efficacy of the SIS for the simple reason that multiple factors have contributed to whether people eligible for SRS-HCP/CSS services have received EF.”(pg. 48). Also, as a part of the SIS study, individuals were randomly selected to be included in the non-EF group from all individuals who are currently receiving regular-tier funding. The report acknowledges that the non-EF group may indeed include individuals who would apply for EF if that opportunity were available. The Developmental Disability Profile (DDP) is not a good dependent variable as it measures personal competency, not support needs. The tier rate derived from the DDP is not a good dependent variable because it indicates only the lowest tier of the three domains measured by the DDP and therefore cannot be equally compared with other tier rates (i.e., a person with a tier 5 in the adaptive domain, a tier 5 in the health domain and a tier 1 in maladaptive domain equals a person with a tier 1 in all three). The converted DDP score is not a good dependent variable because each section of the DDP carries

a different weight. In the end, the SumBASIS was created which is essentially the DDP converted score with all sections carrying the same weight. This still leaves the problem that the DDP is a measure of personal competency and the SIS a measure of support needs. This is solved by the hypothesis, "If, in fact analyses show that the SIS is measuring something other than that measured by the SumBASIS scores, we can hypothesize that what is different would be the indicator of true support need" (pg. 53). As the group understands, it explained that the similarities in the analyses indicate that the SIS and DDP overlap in that support needs and personal competency overlap, and the differences indicate that the SIS is measuring something the DDP isn't, namely support needs. Therefore, the moderate correlations and variances obtained when comparing the SNI to the SumBASIS are a good thing and indicate that the SNI is indeed measuring support needs. One could come to the conclusion that it appears that the hypothesis was created after the fact to explain the analyses, not that the analyses support the hypothesis.

### Comments Regarding the Data

Regarding the data, it was shown that the SNI correlated most highly with the DDP Adaptive domain ( $r=.82$ ), quite a bit less with the DDP Health domain ( $r=.44$ ) and even less with the DDP Maladaptive domain ( $r=.16$ )(pg. 65). Assuming as we have that the need for EF is the result of extraordinary health and behavioral issues, this seems to show that the SNI would be a poor predictor of EF. To support this thought, it is stated on page 67, "In essence, for the EF group, people with high Maladaptive BASIS scores.....have low SIS SNI.....scores, but high SIS Section B scores". In other words individuals with high Maladaptive DDP Scores, presumably those who have a high frequency of maladaptive behaviors, have low SNI scores, or low support needs. This is obviously unlikely.

Other data seem to indicate that the SNI is not a good predictor of EF. On page 77, the Health DDP domain and the combined SNI and Section 3A (exceptional medical support needs) scores are analyzed. It is stated, "In this case, though, when the Section 3 scores were entered into the model, the SNI score dropped from being a significant contributor {to} the model, with the Section 3A Exceptional Medical Support Needs becoming the most significant predictor....". Likewise, when the Maladaptive DDP score and the combined SNI and Section 3B of the SIS were analyzed, "the addition of the section 3B scores eclipsed the impact of the SNI score.....". Lastly, on page 80 it is stated, "In all, the analysis confirmed that the Adaptive BASIS is, of the three BASIS domains, most capable of measuring support needs". But the EF group has made the assumption that extraordinary medical and/or behavioral needs are the indicators of the need for EF. This seems to indicate that not only are measures of personal competence unable to predict EF, but neither is this measure of support needs able to predict EF. It seems to support the assumption made on page 4 that ".....certain medical conditions and challenging behaviors predict that a person will require increased levels of support, *regardless of her or his relative intensity of support needs in other life domains*". (emphasis added)

## Administration of the Assessment

The work group is concerned with the recommended interviewer qualifications outlined on page 7 of the report. Specifically, the report recommends that, "The administration of the SIS should be done by a professional who has completed at least a bachelor-level degree". He does allow for some exceptions for individuals who have certain previous experiences but he does later state that, "The interviewer should also have several years of direct work experience with individuals with intellectual and/or related developmental disabilities and know who to request and verify information from respondents." These requirements may;

1. Significantly limit the pool of qualified interviewers in the State.
2. Impact the cost of administering the assessment.

Page 84 of the report indicates that the average time to complete the SIS was between a half hour and an hour (with variability depending on the complexity of a person's support needs.) It should be noted that the assessment average time may be a somewhat tainted average in that interviews were scheduled for every 30 minutes.

## Group Recommendations

1. Observe Georgia and Utah: It is our understanding that the States of Georgia and Utah are preparing to implement the SIS as a measure of funding need. We suggest that we closely monitor their implementation and learn from their process.
2. An Alternative Tool: The group proposes the implementation of the attached tool, developed by Johnson County Developmental Supports, and modified by the EF Work Group, as the tool used for future determination for need for extraordinary funding in the State of Kansas.
3. It is the recommendation of the work group that SRS contract with JCDS (who will collaborate with the EF work group) to conduct the necessary training across the State for all CDDOs and CSPs.
4. The group recommends that SRS and CDDOs adopt the group recommendations and that training will begin in July, 2006 and be completed no later than October 1, 2006.
5. With regard to identifying who will be assessed for the need for EF, the group makes the following recommendations;
  - A. All individuals who's services are currently reimbursed with EF will be reassessed during FY2007. Persons whose birth date occurs on or after October 1, 2006 shall be reassessed during their birth month. Persons who's birth date occurs in July, August or September of 2006 will be reassessed at the discretion of the CDDO but not later than July 1, 2007.

B. Persons who's services have been reimbursed with EF for at least five consecutive years, and who's 2007 assessment identifies a continued need for EF will, in the future, be reassessed every three fiscal years.

C. Person's will be reassessed annually for the continued need for EF until they have been identified to have a need for EF for five consecutive years, and then will be reassessed every three fiscal years.

6. The group recommends that the CDDO have the discretion to determine who will review the results of assessments and ultimately determine whether or not to recommend to the State a request for EF on behalf of a person. Further the group recommends that a CDDO staff person must complete the justification section of the recommended tool

7. The group recommends that CDDO's have the discretion to accept required information in a substituted format.

### **Summary**

In summary, because of it's high correlation to the Adaptive DDP domain, the SNI may be a good predictor of ordinary support needs. However, the data did not show in any way that the SNI, the only standardized part of the SIS, is a good predictor of extraordinary health or behavioral needs and therefore of the need for EF. More study would need to occur before the SIS could be implemented. It is the recommendation of the group to use the attached tool that measures extraordinary health and behavior needs and is less costly to complete, so that the State has a uniform tool to determine EF until an instrument with standardized measures of health and behavioral needs can be found. Perhaps the creators of the SIS would be interested in standardizing their Exceptional Medical and Behavioral Support Needs section. It is the opinion of the group that the SIS would be an excellent resource for person-centered planning.

## **Extraordinary Funding Work Group Members**

### **Group Members:**

Amy Demoss, CLASS Ltd.

Marsha Dill, *Starkey, Inc.*

Lorraine Harris, *Disability Planning Organization of Kansas*

Michele Johnson, *Cottonwood, Inc.*

Ramona Macek, *Shawnee County Community Developmental Disability Organization*

Shelly May, *Kansas Council on Developmental Disabilities*

Linda Misasi, *Creative Community Living, Inc.*

Jill Montaleone, *Johnson County Developmental Supports*

Sharon Vogel, *Wyandotte County Developmental Disability Organization*

Stephanie Wilson, *Community Living Opportunities, Inc.*

### **Facilitators:**

Clarissa Ashdown, *SRS - Health Care Policy/Community Supports and Services*

Greg Wintle, *SRS - Health Care Policy/Community Supports and Services*